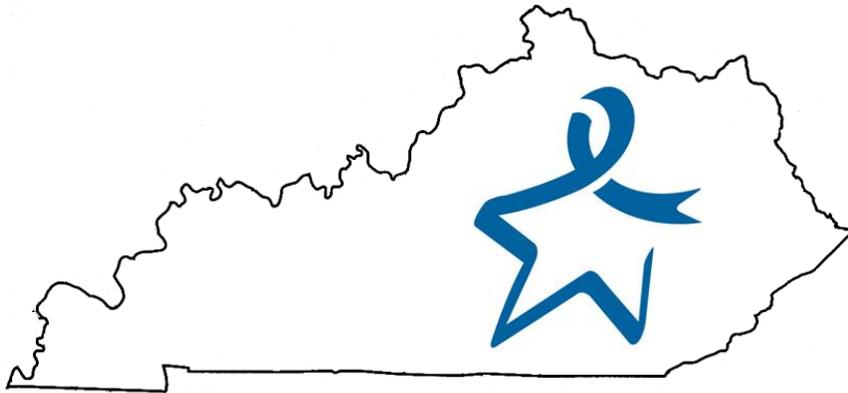


# KENTUCKY COLON CANCER SCREENING PROGRAM RESOURCE MANUAL

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Kentucky Department for Public Health



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Reviewed 2/11

## Using the Kentucky Colon Cancer Screening Program Resource Manual

This manual was created to serve the state and community partners as they develop, implement, and evaluate colon cancer screening and outreach activities that aim to prevent colon cancer. This is a living document, a reference for colon cancer screening guidance and technical assistance that will be updated as the program matures and as the evidence base of proven strategies evolves.

This manual is divided into five sections:

- **Section I:** Kentucky Colon Cancer Screening Program Advisory Committee (KCCSPAC) Members, Goals and Components:  
The first section begins with messages from the KCCSPAC Chair, the KCCSPAC members, recommendations and policy implications, advisory committee overview and program and organizational support.
- **Section II:** The problem of colon cancer in Kentucky:  
This section will begin with Incidence and Mortality data from the Kentucky Cancer Registry, BRFSS data for Kentucky and SEER data from the National Cancer Institute.
- **Section III: How to start a Colon Cancer Pilot Program Pilot Program:**  
This section will begin with a message from the Pike County Health Department Director, but will give recommendations on Quality Assurance, Patient Navigation, screening recommendations from the American Cancer Society and the Centers for Disease Control and Prevention (CDC) as well as follow up recommendations for adverse complication of a colonoscopy.
- **Section IV: Information about our Cancer Partners:** This section will identify our Cancer partners with links to national and local community resources
  - Kentucky Cancer Program
  - American Cancer Society
  - Kentucky Cancer Registry
  - Kentucky Cancer Consortium
  - Colon Cancer Prevention Project
  - Patient Advocate Foundation
- **Section V: Mass Media and Public Awareness:** This section will give contact information about the Kentucky Educational Colon Tour that is available for large audience outreach and education such as the Kentucky State Fair and/or Local

Health Department fairs. This section will include posters and brochures developed by the Kentucky Cancer Program that are available for downloading for use at any of these special events.

- **Appendix**

- Contract templates, Gentrack Data Form, KY Health Department map by county and district, Federal Health Centers map and other topics in the manual.

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# Section I

## **Message from the Colon Cancer Screening Program Advisory Committee**

Dear Colleague:

In 2008, legislation passed through the Kentucky General Assembly called for the development of a colon cancer screening program within the Kentucky Department for Public Health which would address the needs of colon cancer screening of the uninsured. This program is called the Kentucky Colon Cancer Screening Program (KCCSP) and was established to provide outreach and education throughout the state to increase the rates of colon cancer screening and to provide for screening of the uninsured. The program is limited to the amount of funding received.

In May 2010, Governor Steve Beshear held a ceremonial signing of House Bill 72, a measure adding to a 2008 statute that established the colon cancer screening and referral program for uninsured individuals.

KRS §§ 214.544 also created a Colon Cancer Screening Advisory Committee to provide recommendations for overall implementation of the Colon Cancer Screening Program, establish oversight for the public awareness program, and provide an annual report to the Legislative Research Commission, the Governor and the legislature. This document is a result of a collaborative effort between the Kentucky Department for Public Health and the Colon Cancer Screening Advisory Committee.

Although the Centers for Disease Control and Prevention (CDC) have developed a colon cancer screening program, Kentucky is not one of the states funded. The Advisory Committee and program partners will continue to look for sources of funding for screening of the uninsured in order to decrease the burden of colon cancer in Kentucky.

The Kentucky Department for Public Health (DPH) in collaboration with the Pike County Health Department, and the Kentucky Colon Cancer Screening Advisory Committee is implementing a Kentucky Colon Cancer Screening Pilot Program. The Kentucky Colorectal Screening Pilot Program is currently self-funded by the Pike County Health Department, Floyd County Health Department in Eastern Kentucky and the Christian County Health Department in Western Kentucky. The Program's operational objective is to integrate screening services into community clinics across Kentucky, initially beginning with the Pilot Programs and continuing the program statewide

Together we can make a difference in the high rates of colon cancer incidence and mortality in Kentucky through screening, early detection, and community outreach initiatives.

John M. Bennett, MD, MPH  
Chair, KCCSP Advisory Committee

## **Kentucky Colon Cancer Screening Advisory Committee Members**

**John M. Bennett, MD, MPH, Chair**  
*Primary Care/Veteran's Administration*

**Tom Tucker, PhD, MPH, Co-Chair**  
*Director, Kentucky Cancer Registry*

**Claire Albright, JD**  
*Director, Colon Cancer Prevention Project*

**Debra Armstrong, MSW, MPA**  
*Director, UK Kentucky Cancer Program  
East*

**Bill Beam**  
*Colon Cancer Survivor*

**Virginia Bradford, RN**  
*Kentucky African Americans Against  
Cancer*

**Mary Coleman, RN**  
*Department of Medicaid Services*

**Steve Davis, MD**  
*Senior Deputy State Health Officer  
Deputy Commissioner, KDPH*

**Kim Dees**  
*Kentucky Hospital Association*

**B. Mark Evers, MD**  
*Director, UK Markey Cancer Center*

**Whitney F. Jones, MD**  
*Colon Cancer Prevention Project*

**Benjamin Lee Kessinger III, JD**  
*Kinkead & Stilz, PLLC*

**Donald M. Miller, MD, PhD**  
*Director, UL Brown Cancer Center*

**Jennifer Redmond, DrPH**  
*Director, Kentucky Cancer Consortium*

**Ellen Schroeder**  
*American Cancer Society  
West*

**Connie Sorrell**  
*Director, UL Kentucky Cancer Program*

**Alan Stein**  
*Kentucky Legends*

**Representative Rocky Adkins**

**Representative Tom Burch**

**Senator Tom Buford**

## **Kentucky Colon Cancer Screening Program Advisory Committee and Program Overview**

The Kentucky Colon Cancer Screening Program Advisory Committee (KCCSPAC) was established under KRS 214.544 and includes members representing organizations and agencies that are consistently working toward decreasing the incidence, mortality and burden of colon cancer in Kentucky.

The Advisory Committee meets on the third Thursday of each month at 1:30 pm in the Capitol Annex. These meetings began officially in July of 2008 and minutes are recorded and accessible by public record request through the Kentucky Department for Public Health, Division of Prevention and Quality Improvement.

Each monthly meeting is dedicated to the development of the colon cancer screening program and includes presentations from internal experts (e.g., data on prevalence and mortality from the Kentucky Cancer Registry or reports from the Kentucky Cancer Program on public awareness and messaging), presentations from external experts including states with developed programs such as Colorado, review and development of grant applications, program manuals, best practice models for outreach, materials and links on the website and discussion of potential funding sources.

The future direction of the Advisory Committee continues to be a focus on developing a sustainable infrastructure for a statewide colon cancer screening program. The Colon Cancer Screening Program is established for the purposes of:

- (a) Increasing colon cancer screening;
- (b) Reducing morbidity and mortality from colon cancer; and
- (c) Reducing the cost of treating colon cancer among citizens of the Commonwealth.

## **Program and Organizational Support**

The Kentucky Department for Public Health is collaborating with member organizations of the advisory committee as required by statute to develop a colon cancer screening program for Kentucky. The Kentucky Cancer Program and the Kentucky Cancer Consortium provide expertise and connection to coalitions and networks of professional and lay persons working to decrease the burden of cancer in Kentucky.

In the 2010 Special Session of the General Assembly, \$200,000 of coal severance funds were designated to support colon cancer prevention efforts in Martin, Letcher, Floyd, and Pike counties. Two of those counties, Pike and Floyd Co. already have a self-funded pilot program in place with Christian Co recently establishing a self-funded program in Western Kentucky. The Kentucky Department for Public Health will be providing technical assistance to each of these counties and continue to work on integrated cancer screening and prevention efforts with the Kentucky Women's Cancer Screening Program as well as other programs within the Health Care Access Branch

and Chronic Disease Prevention Branch in the Division of Prevention and Quality Improvement and other external partners.

## **KCCSPAC Recommendations and Policy Implications**

Ongoing goals and objectives are directed to accomplishing the following:

1. Utilize an integrated approach to increasing colon cancer screening across Kentucky through partners including local health departments, FQHCs, private providers and hospitals, employers, Medicare, Medicaid, and insurance companies;
2. Develop public awareness campaign as developed by partners within the Advisory Committee;
3. Develop culturally sensitive outreach and education to assist certain high risk groups, such as African American, Appalachians, and other at-risk populations in obtaining timely preventive services;
4. Decreasing barriers to screening and increasing access to particular disparate groups;
5. Development and implementation of pilot projects in strategic areas that will provide an immediate impact and outreach for at risk groups;
6. Development of a patient navigation model for improving access to recommended cancer screening services, follow-up, diagnosis and treatment in medically underserved populations;
7. Development of an electronic system for clinical and cost data collection for colon cancer screening which is linked to the Kentucky Cancer Registry per guidelines of the CDC.

# Section II

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## **The Problem of Colon Cancer in Kentucky**

Colon cancer is a significant health problem in the United States. It is the third most commonly occurring cancer among both men and women. Approximately 150,000 new cases of colorectal cancer are diagnosed each year and nearly 50,000 people die from the disease each year. Colorectal cancer accounts for 10% of all cancer deaths in the U.S.<sup>1</sup>

According to the Kentucky Cancer Registry, there were 12,458 cases of invasive colorectal cancer diagnosed in Kentucky during 2002-2006. Of those diagnosed, 6,329 were men (50.8%) and 6,129 were women (49.2%). By age group there were 5,442 diagnosed between 50 and 70 years of age and 5,861 diagnosed over age 70. In addition, 1,155 were less than 50 years of age at diagnosis.

Many cases of colorectal cancer could be prevented through appropriate screening. Most colon cancers develop from adenomatous polyps which are noncancerous growths in the colon and rectum. Detecting and removing polyps by screening asymptomatic age-eligible patients can actually prevent the disease from occurring. Furthermore, appropriate screening for colorectal cancer will result in detecting a number of cancers at an earlier stage when they are more likely to be cured and the treatment is less extensive.<sup>2</sup> The American Cancer Society estimates that 9 out of 10 colorectal cancers could be prevented or cured by screening and regular check-ups.

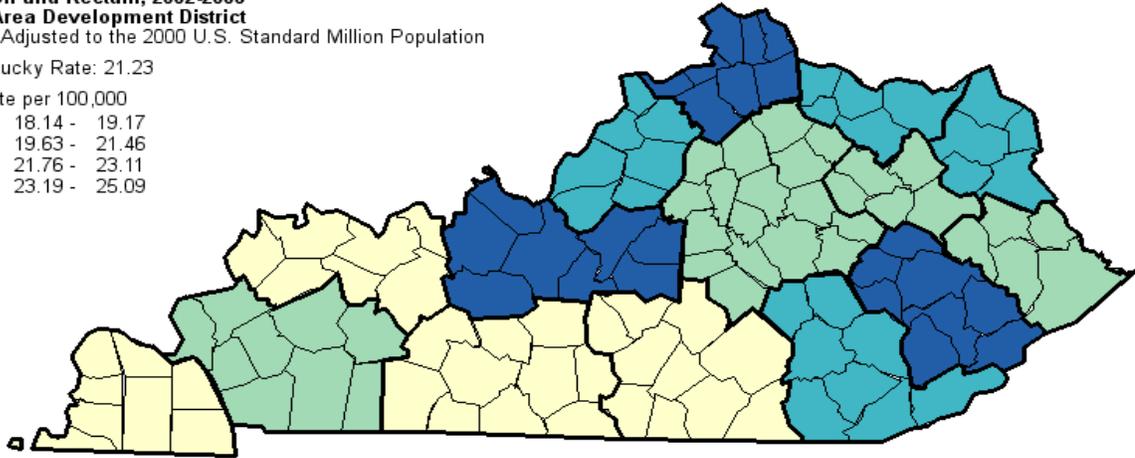
The value of colorectal cancer screening is clear. Despite the preventable nature of the disease, the National Cancer Institute website for state cancer profiles indicates that Kentucky has the third highest mortality from colon cancer as compared to all other states and the District of Columbia for the most recent year of data which is 2006. When data is trended over a period of time (2002-2006) both males and females in Kentucky have the second highest incidence rate and the second highest mortality rate from colorectal cancer among all of the states in the U.S. (Figure 1 and 2). More than 9% of all cancer deaths in Kentucky are due to colorectal cancer.<sup>3</sup>

**Figure 1**

**Age-Adjusted Cancer Mortality Rates in Kentucky  
Colon and Rectum, 2002-2006  
By Area Development District**  
Age-Adjusted to the 2000 U.S. Standard Million Population

Kentucky Rate: 21.23

Rate per 100,000  
 18.14 - 19.17  
 19.63 - 21.46  
 21.76 - 23.11  
 23.19 - 25.09



Data accessed August 19, 2010.  
 Based on data released July 22, 2009.  
 Copyright (C) 2010 Kentucky Cancer Registry

<b>Cancer Mortality Rates by Area Development District in Kentucky</b>				
<b>Colon and Rectum, 2002-2006</b>				
<b><u>Area Development District</u></b>	<b><u>Population at Risk</u></b>	<b><u>Deaths</u></b>	<b><u>Crude Rate</u></b>	<b><u>Age-adjusted Rate</u></b>
Kentucky River	590805	152	25.73	25.09
Northern Kentucky	2049125	419	20.45	23.27
Lincoln Trail	1253091	275	21.95	23.19
Kipda	4475875	1057	23.62	23.11
Buffalo Trace	278976	70	25.09	22.58
Cumberland Valley	1198749	275	22.94	22.26
Fivco	680401	170	24.99	21.76
Big Sandy	785976	171	21.76	21.46
Gateway	392526	82	20.89	20.59
Bluegrass	3581361	664	18.54	19.89
Pennyrile	1098941	236	21.48	19.63
Barren River	1319381	263	19.93	19.17
Purchase	965219	236	24.45	18.73
Green River	1040661	216	20.76	18.66
Lake Cumberland	987554	215	21.77	18.14
<b>STATE</b>	<b>20698641</b>	<b>4501</b>	<b>21.75</b>	<b>21.23</b>
<b>Note: All rates are per 100000. Rates are age-adjusted to the 2000 U.S. Standard Million Population.</b>				
<b>Data accessed August 19, 2010. Based on data released July 22, 2009.</b>				

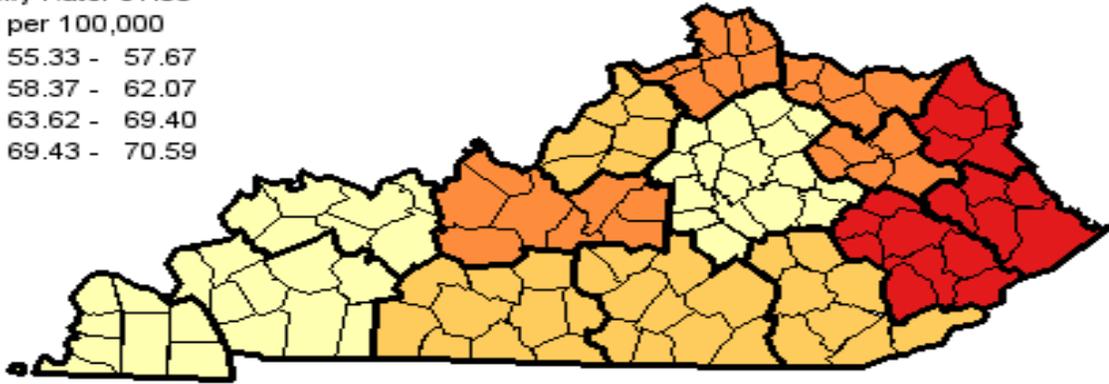
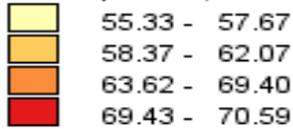
Figure 2

**Age-Adjusted Cancer Incidence Rates in Kentucky  
Colon and Rectum, 2003-2007  
By Area Development District**

Age-Adjusted to the 2000 U.S. Standard Million Population

Kentucky Rate: 61.00

Rate per 100,000



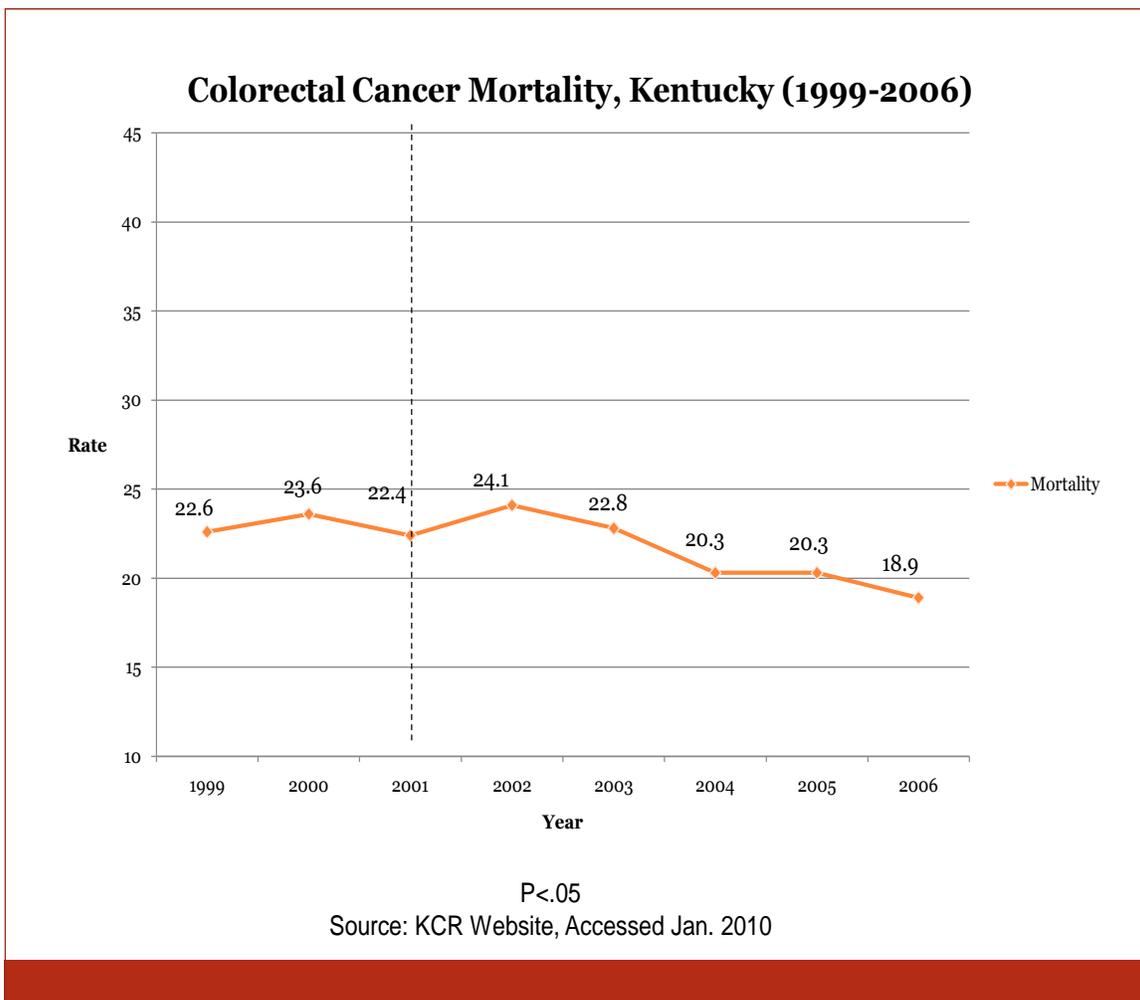
Data accessed September 13, 2010.  
Based on data released January 7, 2010.  
Copyright (C) 2010 Kentucky Cancer Registry

<b>Cancer Incidence Rates by Area Development District in Kentucky</b>				
<b>Colon and Rectum, 2003-2007</b>				
<u>Area Development District</u>	<u>Population at Risk</u>	<u>Cases</u>	<u>Crude Rate</u>	<u>Age-adjusted Rate</u> ▼
<a href="#">Kentucky River</a>	588569	444	75.44	70.59
<a href="#">Big Sandy</a>	783900	590	75.26	69.62
<a href="#">Fivco</a>	681241	558	81.91	69.43
<a href="#">Buffalo Trace</a>	280055	220	78.56	69.40
<a href="#">Lincoln Trail</a>	1262072	826	65.45	65.51
<a href="#">Northern Kentucky</a>	2074255	1211	58.38	63.69
<a href="#">Gateway</a>	395088	260	65.81	63.62
<a href="#">Kipda</a>	4514208	2929	64.88	62.07
<a href="#">Cumberland Valley</a>	1201853	767	63.82	59.58
<a href="#">Lake Cumberland</a>	992896	698	70.30	58.68
<a href="#">Barren River</a>	1334148	822	61.61	58.37
<a href="#">Bluegrass</a>	3625176	2017	55.64	57.67
<a href="#">Purchase</a>	967391	695	71.84	56.70
<a href="#">Pennyrile</a>	1104433	671	60.76	55.72
<a href="#">Green River</a>	1042910	654	62.71	55.33
<b><a href="#">STATE</a></b>	<b>20848195</b>	<b>13362</b>	<b>64.09</b>	<b>61.00</b>

Note: All rates are per 100,000. Rates are age-adjusted to the 2000 U.S. Standard Million Population.

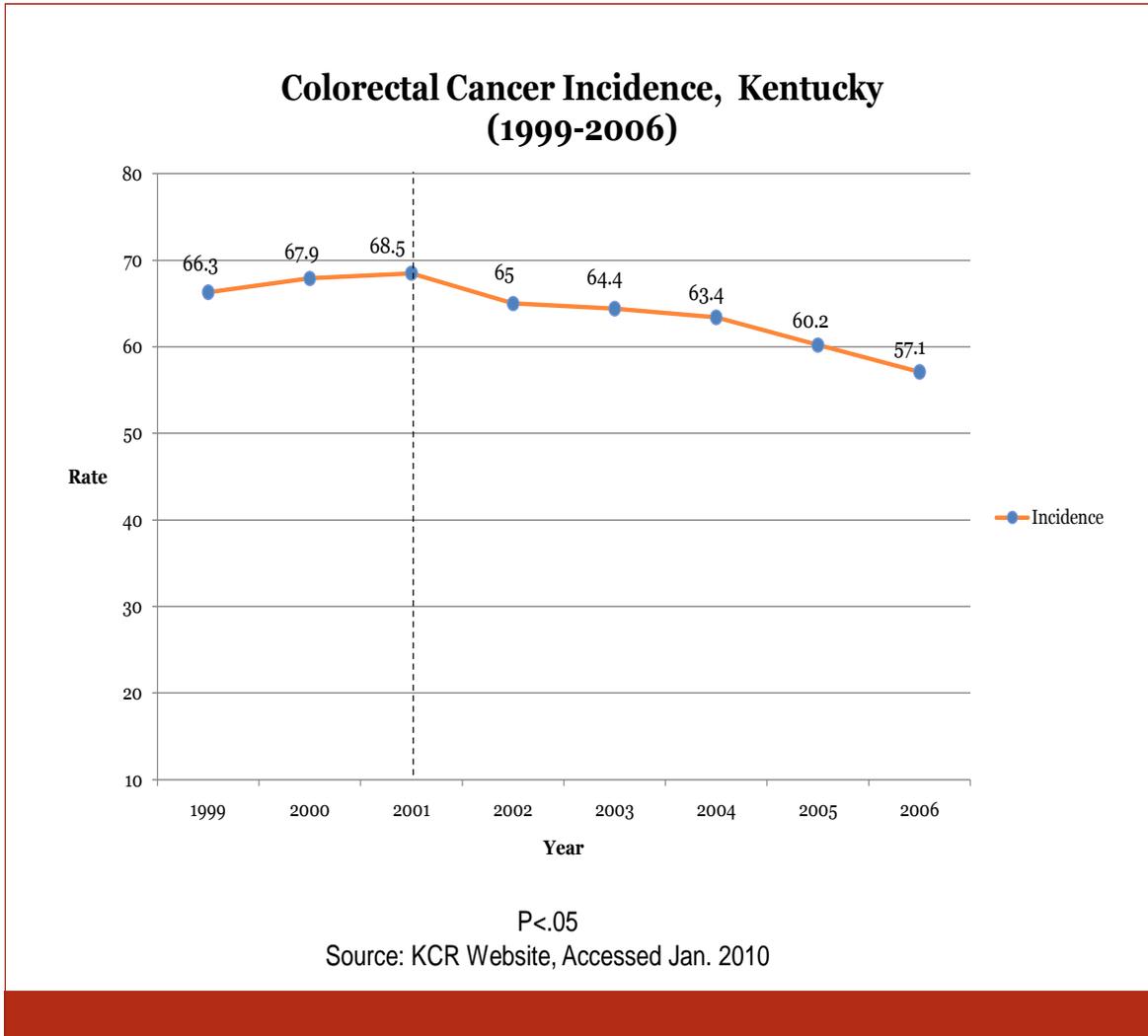
Data accessed September 13, 2010. Based on data released January 7, 2010.

**Figure 3**



Decreases in colorectal cancer incidence and mortality in Kentucky have been dramatic. These changes represent a true reduction in the number of people getting colorectal cancer and the number of people dying from colorectal cancer in the state. However, there is still considerable work to be done. More than one-third of the age-eligible Kentucky population has never had a screening colonoscopy or sigmoidoscopy. The colorectal cancer incidence and mortality rates could be reduced by an additional 15% if the remaining one-third of the age-eligible Kentucky population was screened. In order to successfully accomplish this important public health objective, it will be necessary to have funding for screening the uninsured, age-eligible population. The uninsured represent a large proportion of the age-eligible individuals in Kentucky who have never been screened for colorectal cancer. Screening this vulnerable, at-risk population will not only further reduce the incidence and mortality rates in the state, but it will also substantially reduce the cost of treating preventable or more advanced cases of colorectal cancer.

**Figure 4**



In 2001, it was noted that Kentucky had the lowest colorectal cancer screening rate compared to all other states. To correct this situation, an intensive effort aimed at improving the colorectal cancer screening rate in the state was initiated at the end of 2001. This effort was coordinated through the Kentucky Cancer Consortium (KCC) and included active contributions from the DPH, the ACS, the Kentucky Cancer Program (KCP), the Colon Cancer Prevention Project (C2P2), the KCR, and many others. Since this initiative was implemented, both the colorectal cancer incidence and mortality rates in Kentucky decreased by 16% as shown in the following two graphs. These changes are statistically significant and consistent with what would be expected to occur with increased screening.

## **Section III**

## Message from Paul Hopkins, Director, Pike County Health Department

### “How to Start a Colon Cancer Screening Pilot Program”

Dear Colleague:

My initial plan was to address Men’s Cancer issues, as there is no program in the County or State, and therefore I made a request for \$ 10,000 dollars to my Board of Health. My plan was to develop a program for men that would be recognized for excellence as the Breast and Cervical Cancer Program had become. However, due to overwhelming requests, we developed a Colorectal Cancer program for both men and women. The following are recommendations from the Pike County Health Department for any health departments that are interested in starting a colon cancer pilot program in their county:

- The Director will need to obtain the statistics for their county to justify and support any request from their Board of Health to develop any new program.
- The Directors will need to define their county health needs.
- Identify partnerships providers or clinics are addressing the same issue; develop a working relationship with the local Federally Qualified Health Centers, Community Clinics and other providers such as physicians and hospitals who will work for Medicaid rates or less or no cost.
- Develop contracts using the Breast and Cervical Program contracts as guidelines.
- No funds are used for treatment, hospital expenses or other expenditures. If needed, the Health Department will help to find resources to cover other costs.

My main objective at Pike County Health Department was that **FREE SCREENINGS** are better than **NO SCREENINGS** and this is the first obstacle that will prevent a patient from taking the first step. While some Directors felt it wasn't **APPROPRIATE** to just do screenings and not pay for other costs and treatment, my answer to that was "While they were waiting to make it **APPROPRIATE**, **we have screened patients and saved lives**".

Paul Hopkins

Director, Pike County Health Department

## SCREENING RECOMMENDATIONS

Your program should support informed decision making in screening, a process that each patient with his/her provider needs to complete. This screening and surveillance tip sheet is distributed in conjunction with the Kentucky Medical Association, courtesy of the Colon Cancer Prevention Project. For copies of this tip sheet and other materials, please visit [www.coloncancerpreventionproject.org](http://www.coloncancerpreventionproject.org)

Risk	Average	High		
<b>Definition or Diagnosis</b>	No risk factors other than $\geq$ age 50 and $\geq$ age 45 for African Americans	HNPCC: Hereditary Nonpolyposis Colorectal Cancer <u>or</u> Family or personal history of early ( $<$ age 50) ovarian, endometrial or colorectal cancers	Family history of FAP (familial polyposis) in a first degree relative (parent, sibling, or child)	Ulcerative colitis (UC) <u>or</u> Crohn's colitis (CC)
<b>Begin Screening</b>	Age 50 <u>or</u> age 45 for African Americans	By age 20-25	At puberty	Personal history of pan ulcerative colitis $\geq$ 8 years, left sided colitis $\geq$ 15 years, or longstanding CC
<b>Preferred Screening Strategy</b>	Colonoscopy every 10 years	Colonoscopy every 2 years, genetic testing and referral to a specialist	Flexible sigmoidoscopy or colonoscopy, genetic testing, and referral to a specialist	Colonoscopy every 1-2 years
<b>Alternative Screening Strategies</b> from the American Cancer Society	<ul style="list-style-type: none"> <li>• Flexible sigmoidoscopy every 5 years</li> <li>• Double contrast barium enema every 5 years</li> <li>• CT colonography (virtual colonoscopy) every 5 years</li> <li>• Fecal occult blood test annually</li> <li>• Fecal immunochemical test annually</li> <li>• Stool DNA test (sDNA), interval uncertain</li> </ul>	No alternative screening strategy for higher risk individuals other than colonoscopy		
Note: Kentucky and Indiana mandate coverage of colorectal cancer screening tests recognized by the American Cancer Society				

## Recommendations for Individuals with Family History of CRC or Adenomatous Polyp

Relationship	Screening Recommendations	Surveillance
First-degree relative[s] with colorectal cancer diagnosed at age < 60 years	Colonoscopy at age 40 or 10 years younger than affected relative, whichever is younger	If normal, repeat every 3-5 years
First-degree relative[s] with colorectal cancer diagnosed at $\geq$ 60 years	Colonoscopy at age 40	If normal, repeat every 10 years
First-degree relative[s] with adenomatous polyp < 60 years	Colonoscopy at age 40 or 10 years younger than affected relative, whichever is younger	If normal, repeat every 5 years
First-degree relative[s] with adenomatous polyp > 60 years	Colonoscopy for screening age individualized	If normal, same as average risk
Second or third-degree relative with cancer or polyps	Colonoscopy as average risk individuals	If normal, same as average risk

**General Recommendations for Surveillance** (Complete colonoscopy is the only recommended procedure for surveillance.)

Colonoscopic Findings	Recommendations*
1 or 2 tubular adenomas, <1 cm, low grade dysplasia	Next colonoscopy in 5 years
$\geq$ 3 adenomas <u>or</u> Adenoma $\geq$ 1 cm <u>or</u> Villous histology or high grade dysplasia	Next colonoscopy in 3 years
> 10 adenomas on colonoscopic exam <u>or</u> inadequate colon preparation	Next colonoscopy in < 3 years
Colon cancer, resected	Clearance of remainder of the colon at or around time of resection, followed by colonoscopy at 1 year, then at 3 years and then at 5 year intervals if results are normal
Rectal cancer, resected	Clearance of remainder of the colon at or around time of resection, followed by colonoscopy at 1 year, then at 4 years and then at 5 year intervals if results are normal
Pan ulcerative colitis >8 years, Left-sided ulcerative colitis $\geq$ 15 years, Longstanding Crohn's colitis	Colonoscopy every 1-2 years with systematic Biopsies to detect dysplasia
Sessile adenomas that are removed piecemeal	Follow-up colonoscopy in 2-6 months to verify complete removal of adenomas

\*All recommendations are based on the assumption that colonoscopy was completed with adequate bowel prep and that the exam reached the cecum.

A repeat examination may be warranted for incomplete bowel prep or if the colonoscopy was not completed to the cecum.

**Comprehensive Colonoscopy Documentation  
to be sent to primary care physician**

✓ Pre-procedure risk assessment	✓ Quality of the bowel prep		1. Location
✓ Depth of insertion (i.e. to cecum or other landmark)	✓ Duration of colonoscopic exam	✓ Complete description of polyp(s) found:	2. Size
	✓ Recommendation for follow-up		3. Number
			4. Gross Morphology

Full article available at [CA Cancer J Clin 2008 58: 130-160](#)

### **Adequacy of Colonoscopy**

“Adequate” colonoscopy is defined as reaching the cecum and having colonic preparation sufficient to visualize 90% of the colonic mucosa. The colonoscopy procedure report should detail whether the cecum was reached and whether the endoscopist visualized the colonic mucosa adequately.

### **Findings of Colonoscopy**

Colonoscopist’s report of optical colonoscopy findings including polyp(s), mass, lesion/tumor, other lesions (hemorrhoids, diverticular disease, varices, inflammatory bowel disease (ulcerative colitis and Crohn’s disease of the colon).

Including:

- Number of lesions
- Description (e.g., flat, raised, sessile, pedunculated, bleeding, irregular, etc.), size, and location of each lesion seen
- Whether there was:
  - biopsy during colonoscopy with removal of entire lesion(s);
  - biopsy without removal of entire lesion(s);
  - no biopsy during colonoscopy; and
  - management of polyp/lesion (tattoo of site; saline lift prior to biopsy, etc.)
- Whether additional surgery or procedure is needed at this time (specify what is needed), or that there is no need for additional surgery or procedure at this time

### **Colonoscopist’s recommendation**

Colonoscopist’s recommendation for date of next colonoscopy or other testing is based on the adequacy of the colonoscopy, the optical findings, the results of pathology, and the client’s risk category. If the recommendation depends on the results of the histological evaluation of a polyp then the colonoscopist should provide recommendations contingent on the pathology results (If polyp is adenomatous, repeat colonoscopy in 5 years, if hyperplastic repeat in 10 years etc). The precise recommendation will sometimes not be available in the colonoscopy report as it is generated prior to the pathology being available so would encourage the colonoscopist to provide contingency recommendations.

### **Pathology Report**

A polyp or lesion should be classified by standard pathologic criteria and should include the following:

- Type of polyp or lesion: tubular adenoma; villous adenoma; tubulovillous adenoma; serrated adenoma; hyperplastic polyp; other (mucosal polyp,

inflammatory, pseudopolyp, submucosal polyp [lipoma, carcinoid, metastatic tumor, etc.]).

- Degree of dysplasia: low grade dysplasia (mild dysplasia, moderate dysplasia), high grade dysplasia (including severe dysplasia, carcinoma in situ, and intramucosal carcinoma).
- Presence of involvement of stalk/margin: If neoplasia (adenoma or cancer) is present, determine whether the stalk or margin of the specimen is free of involvement.

**Note** This applies to larger polyps removed by snare excision. It is often not possible to evaluate the margins of small polyps removed by biopsy alone.

**An invasive carcinoma on biopsy or polypectomy specimen should be classified as follows:**

- **Differentiation**

Note whether the carcinoma is well, moderately, or poorly differentiated

If carcinoma is arising in adenomatous polyp:

- Presence or absence of lymphatic/vascular invasion
- Margins: Note whether the margin is involved; distance of the carcinoma from the margin/stalk, or distance of the carcinoma from the cauterized margin of the specimen.

- **Stage of disease**

Based on biopsy results, diagnostic tests, surgical findings, and pathology, the stage of disease should be determined for the individual patient. This should include the American Joint Committee on Cancer (AJCC) staging by TNM classification of the tumor, nodes, and metastases.

- **Treatment**

Based on the findings on colonoscopy or other screening/diagnostic tests and the further evaluation, the usual and customary treatments will be recommended by the medical care provider(s) on a case by case basis:

- No further treatment necessary
- Ablation or excision of lesions during colonoscopy
- Surgery
- Chemotherapy
- Radiation Therapy

# **Follow-up of Colonoscopy and Other Testing**

## **Inadequate Colonoscopy**

If a provider determines that a colonoscopy is “inadequate,” the provider should determine if and when additional procedures are necessary to complete this screening for colon cancer (repeating the colonoscopy). Follow up testing due to inadequacy of an initial test will need to be documented in the patients’ record.

## **Adverse Events**

Once an adverse event has occurred it must be reported to the program manager within 72 hours with supporting documentation. Complications during a colonoscopy can include perforation, bleeding, reaction to anesthetic, tachycardia, bradycardia, prolonged somnolence and infection or death.

## **Colon Cancer Diagnosis**

If a colon cancer diagnosis has occurred, the clinic partner will assess if the patient is eligible for a funding source (Medicare/Medicaid, Charity or Disproportionate Share). Treatment providers will send reports detailing the services provided for the patient to the referring clinic partner and the patient navigator as required for appropriate data collection. Clinics will take appropriate measures to ensure the provision of follow-up services by patients with abnormal screening results and be documented in the patient’s medical record

## **Case Management**

All enrolled patients with an abnormal screening result must be assessed for their need of case management services. Case management services will conclude when a client initiates treatment, refuses treatment, or is no longer eligible for the program, or when a patient concludes colon cancer treatment if finished and will be documented in the patient’s medical record.

# **Guidelines for Colonoscopy Surveillance after Polypectomy: A Consensus Update by the U.S. Multi-Society Task Force on Colorectal Cancer and the American Cancer Society**

**Full Article [CA Cancer J Clin 2006;56:143-159](#)**

## **Surveillance Recommendations**

- 1. Patients with small rectal hyperplastic polyps** should be considered to have normal colonoscopies, and therefore the interval before subsequent colonoscopy should be 10 years. An exception is patients with a hyperplastic polyposis syndrome. They are at increased risk for adenomas and colorectal cancer and need to be identified for more intensive follow up.
- 2. Patients with only one or two small (< 1 cm) tubular adenomas with only low-grade dysplasia** should have their next follow-up colonoscopy in 5 to 10 years. The precise timing within this interval should be based on other clinical factors (such as prior colonoscopy findings, family history, and the preferences of the patient and judgment of the physician).
- 3. Patients with 3 to 10 adenomas, or any adenoma > 1 cm, or any adenoma with villous features, or high-grade dysplasia** should have their next follow-up colonoscopy in 3 years providing that piecemeal removal has not been done and the adenoma(s) are completely removed. If the follow-up colonoscopy is normal or shows only one or two small tubular adenomas with low-grade dysplasia, then the interval for the subsequent examination should be 5 years.
- 4. Patients who have more than 10 adenomas at one examination** should be examined at a shorter (< 3 years) interval established by clinical judgment, and the clinician should consider the possibility of an underlying familial syndrome.
- 5. Patients with sessile adenomas that are removed piecemeal** should be considered for follow up at short intervals (2 to 6 months) to verify complete removal. Once complete removal has been established, subsequent surveillance needs to be individualized based on the endoscopist's judgment. Completeness of removal should be based on both endoscopic and pathologic assessments.
- 6. More intensive surveillance is indicated when the family history is suggestive of any of the familial colon cancer syndromes.**

## **Additional Surveillance Considerations**

1. The present recommendations assume that colonoscopy is complete to the cecum and that bowel preparation is adequate. A repeat examination should be done if the bowel preparation is not adequate before planning a long-term surveillance program.
2. There is clear evidence that the quality of examination is highly variable. A continuous quality improvement process is critical to the effective application of colonoscopy in colorectal cancer prevention.
3. A repeat examination is warranted if there is a concern that the polyp is incompletely removed, particularly if it shows high-grade dysplasia.
4. Endoscopists should make clear recommendations to primary care providers about when the next colonoscopy is indicated.
5. Given the evolving nature of guidelines, it is important that physicians and patients should remain in contact so that surveillance recommendations reflect changes in guidelines.
6. Pending further investigation, performance of fecal occult blood test is discouraged in patients undergoing colonoscopic surveillance.
7. Discontinuation of surveillance colonoscopy should be considered in persons with serious comorbidities with less than 10 years of life expectancy, according to the clinician's judgment.
8. The application of evolving technologies such as chromoendoscopy, magnification endoscopy, narrow-band imaging, and computed tomography colonography are not established for post-polypectomy surveillance at this time.

# **Guidelines for Colonoscopy Surveillance after Cancer Resection: A consensus Updated by the American Cancer Society and the U.S. Multi-Society Task Force on Colorectal Cancer**

Full Article [CA Cancer J Clin 2006;56-160-167](#)

## **Post-Cancer Resection Surveillance Colonoscopy Recommendations**

- 1. Patients with colon and rectal cancer should undergo high quality perioperative clearing.** In the case of nonobstructing tumors, this can be done by preoperative colonoscopy. In the case of obstructing colon cancers, computed tomography colonography with intravenous contrast or double contrast barium enema can be used to detect neoplasm's in the proximal colon. In these cases, a colonoscopy to clear the colon of synchronous disease should be considered 3 to 6 months after the resection if no unresectable metastases are found during surgery. Alternatively, colonoscopy can be performed intraoperatively.
- 2. Patients undergoing curative resection for colon or rectal cancer should undergo a colonoscopy 1 year after the resection (or 1 year following the performance of the colonoscopy that was performed to clear the colon of synchronous disease).** This colonoscopy at 1 year is in addition to the perioperative colonoscopy for synchronous tumors.
- 3. If the examination performed at 1 year is normal, then the interval before the next subsequent examination should be 3 years.** If that colonoscopy is normal, then the interval before the next subsequent examination should be 5 years.
- 4. Following the examination at 1 year, the intervals before subsequent examinations may be shortened if there is evidence of hereditary non-polyposis colorectal cancer or if adenoma findings warrant earlier colonoscopy.**
- 5. Periodic examination of the rectum for the purpose of identifying local recurrence, usually performed at 3 to 6 month intervals for the first 2 or 3 years, may be considered after low anterior resection of rectal cancer.** The techniques utilized are typically rigid proctoscopy, flexible proctoscopy, or rectal ultrasound. These examinations are independent of the colonoscopic examinations described above for detection of metachronous disease.

## **Additional Recommendations Regarding Post-Cancer Resection Surveillance Colonoscopy**

1. These recommendations assume that colonoscopy is complete to the cecum and that bowel preparation is adequate.
2. There is clear evidence that the quality of examinations is highly variable. A continuous quality improvement process is critical to the effective application of colonoscopy in colorectal cancer prevention.
3. Endoscopists should make clear recommendations to primary care physicians about when the next colonoscopy is indicated.
4. Performance of fecal occult blood test is discouraged in patients undergoing colonoscopic surveillance.
5. Discontinuation of surveillance colonoscopy should be considered in persons with advanced age or comorbidities (with less than 10 years of life expectancy), according to the clinician's judgment.
6. Surveillance guidelines are intended for asymptomatic people. New symptoms may need diagnostic workup.
7. Chromoendoscopy (dye-spraying) and magnification endoscopy are potentially helpful but not established as essential to screening or surveillance.

# Program Evaluation

## Overview

A planned evaluation of your program will provide you with information about clinical outcomes necessary for assessing program efficacy. Evaluation will also provide information about process outcomes that will measure program reach, efficiency and quality of services provided. The role of the evaluation is to define clinical and process outcomes of interest, and to standardize collection and receipt of these data from all clinic partners. The evaluation team will compile data, provide feedback to clinic partners, and produce regular reports.

## Minimal Data Elements (MDEs) Gen Track Database

### Data Collection

MDE's, which are provided as a standard from the Centers of Disease Control and Prevention, are a set a standardized data elements use to collect demographic and clinical information on patients screened by the screening program. Participating clinics should collect the minimal data elements for all patients screened in the program and provide these data within 30 days of the service through entry into the data system. The KDPH staff will work with clinic partners and provide technical assistance to assure that they have the training to collect the necessary data. Additional measurements of the impact of your program include; state-wide colon cancer screening rates both among the uninsured and the insured population from the Behavioral Risk Factor Surveillance Survey collected before and after the initiation of the Program.

The Kentucky Department for Public Health has developed a web based database, Gen Trac that clinics can use to collect and maintain evaluation data. The system provides a definition and standardization of collection of data elements, and will allow aggregation of data and link to the Kentucky Cancer Registry. Screening and diagnostic data collected on patients reported in the MDE's will meet all data quality standards set by CDC. Please see appendix for a copy of Colon Cancer MDE

### Some examples of MDE include:

#### Demographic information:

- Patient age
- Gender
- Family history of colon cancer
- Symptoms at time of screening

## **Clinical outcomes:**

- Type of screen performed (colonoscopy, flexible sigmoidoscopy, barium enema), FIT, FOBT
- Screening outcome (completed, inadequate exam, no show)
- Screening result (normal, positive-biopsied)
- Pathology result (polyp size, histology)
- Colon cancer characteristics (size, histology, location, stage and grade)

## **Process related outcomes:**

- Outreach: number of individuals (patients) contacted via mail, telephone, etc
- Response to outreach efforts (How did clients hear about Program?)
- Screening completion rate: # screened / # appointments scheduled
- Number of patients provided assistance with transportation and/or translation
- Quality and timeliness of care
- Patient satisfaction with screening program

## **Data Audits**

Evaluation staff from your program should conduct regular data audits. The purpose of the audit is to assure patient eligibility and accuracy of data submitted, and to monitor quality of care provided. Audit procedures will also serve to evaluate processes established for the Program. Clinic partners will need to provide evaluation staff access to medical charts and other supplementary data related to the screening procedure, patient in-reach and out-reach activities, and patient navigation. This may include colonoscopy and pathology reports, and patient navigation logs.

## **Explanation of Evaluation Terms**

### **Screening Outcome**

- Completed: screen was successfully completed
- Inadequate Exam: any screening exam that was not able to be completed due to poor preparation, abnormalities, or any other reason
- No Show: patient did not show up for scheduled screening exam

### **Screening Result**

- Negative: colonoscopy **without** tissue removed and/or polyps identified
- Positive: colonoscopy **with** polyps detected and/or tissue removed for pathological review.

## **Pathology Result**

**In cases with multiple biopsies, report most severe histology. Histologies are listed below in decreasing order of severity (colon cancer = most severe)**

- Colon cancer: includes adenocarcinoma, carcinoma, carcinoid tumor or other neoplasia
- Adenoma/pre-colon cancerous: includes adenomatous, villous, tubular, tubulovillous or pre-colon cancerous finding
- Benign/hyperplastic: any polyp identified as benign or hyperplastic
- Other/unknown
- No diagnostic abnormality: biopsy taken of completely normal tissue.

## **Medical Quality Assurance**

A committee with a recommended make up of physicians, nurses, patient navigators, and survivors should meet either in person or via conference call quarterly. The chairman of the committee will be available to review individual patient questions and will get advice from the other committee members as needed and the individual recommendations will be reviewed at each committee meeting.

The Medical Quality Assurance Committee has an advisory role in:

1. Developing and periodically assessing your screening and surveillance guidelines to be used for determination of eligibility for your program
2. Providing guidance to staff regarding questions about specific patients eligibility
3. Periodically reviewing the entry criteria of subjects accrued to the program
4. Providing a resource to staff regarding medical decisions about treatment of colon cancers detected by the program
5. Reviewing any medical complications related to participation in the program.

# Clinical Support and Patient Navigation

## Overview

The primary purpose of the navigator and clinic outreach component of the project is to improve health care delivery to populations who have limited or no access to the health care system. The role of a patient navigator was created to eliminate the barriers and guide patients through the medical system. Patient navigators work to identify health care obstacles and help patients get the best possible care. In this project, navigators are involved in clinic in reach, scheduling screening, and preparation, diagnosis, and follow up, all in a culturally competent manner. The activities and services include:

1. Assisting patients through the screening process to assure that people show up for their appointment and prepare adequately for the examination
2. Helping to increase the awareness of clinic staff about colon screening and colon cancer
3. Assisting patients in follow up of abnormal screening results or colon cancer diagnosis
4. Recording and reporting screening outcomes to the Program
5. Participating in training sessions and teleconferences for navigation.

A Navigator Guidebook, to be developed, will explain the roles and limitations of a Colon Cancer Screening Program Navigator. The clinic may also ask the navigator to assume the responsibility of verification of lawful Kentucky residence, insurance and income along with specific information about the Program, colon cancer screening, and diagnosis. These activities may be carried out by one designated person or shared among clinic personnel.

## The goals of a colonoscopy patient navigator program are:

- **Eliminate barriers to care.**
- **Improve patients' understanding of colonoscopy.**
- **Reduce "no-show" rates.**
- **Improve colon cancer screening rates.**

## How the Patient Navigator Works

The patient navigator is an integral part of a colonoscopy navigator program. Navigators work with colonoscopy patients to "navigate" the health care system and access appropriate resources and services. They are trained, culturally sensitive health care workers who help patients overcome barriers to quality care. When a patient is referred by their doctor for a colonoscopy, the navigator helps

explain why the procedure is important and how to prepare for it. The navigator may be helps alleviate fears about the procedure by explaining what the patient can expect and answering questions. The navigator may be located at the local health department, hospital or at the physician's office.

### **Navigators also assist with many tasks, such as:**

- Linking patients to resources and services.
- Contacting patients to confirm or reschedule appointments.
- Helping patients make follow-up appointments.
- Conducting outreach to non-adherent patients.
- Tracking interventions and outcomes.

## **Benefits of Patient Navigation**

**There are many benefits to establishing a patient navigator program, such as:**

### **For the Hospital**

- Better coordination and continuum of care.
- Improved colon cancer screening rates.
- Improved patient outcomes.
- More colonoscopy referrals.
- Increased support of direct referrals.

### **For the Provider**

- Streamlined GI suite practices.
- Navigators help free up provider time by:
  - Taking on logistical and educational tasks.
  - Helping patients arrive on time and prepared.
  - Tracking interventions and outcomes.

### **For the Patient**

- Enhanced access to care and services.
- Reduced barriers to care (e.g., financial, insurance, education)
- Increased patient satisfaction

## **Section IV**

# American Cancer Society

The American Cancer Society (ACS) is a nationwide, community-based voluntary health organization. Headquartered in Atlanta, Georgia, the ACS has state divisions and more than 3,400 local offices.

For more information about colorectal cancer resources, click on the link; [↗](#)

## Kentucky Cancer Registry

In 1990, the State General Assembly passed legislation that formally established The Kentucky Cancer Registry (KCR) as the official population-based central cancer registry for the Commonwealth of Kentucky. KCR is currently a part of both the National Cancer Institute's Surveillance Epidemiology and End Results (SEER) program and the Centers for Disease Control and Prevention's National Program of Cancer Registries (NPCR). KCR is an active participant in the North American Association of Central Cancer Registries (NAACCR).

### History of Cancer Reporting in Kentucky

Kentucky Cancer Registry (KCR) began as a voluntary reporting system in 1986. In April of 1990, the State General Assembly passed legislation that formally established KCR as the population-based central cancer registry for the Commonwealth. The legislation provided recurring funding for staff, travel and computer equipment. Mandatory reporting to KCR officially began January 1, 1991.

All Kentucky acute care hospitals and their associated outpatient facilities are required to report each case of cancer using the Cancer Patient Data Management System (CPDMS) developed by KCR. The larger hospitals (those diagnosing or treating more than 100 new primary cancer cases annually) are required to have their own tumor registrar(s). These larger hospitals are divided into three geographic regions. Three Regional Coordinators are employed by KCR to work with the larger institutions to ensure the quality, accuracy, and timeliness of the data reported. All hospital-based registrars are required to attend extensive formal training programs before they begin abstracting cases. The KCR Regional Coordinators spend one day each month in each of these larger facilities providing additional training, reabstracting cases for quality control and helping the hospital-based registrars prepare reports from the data. The smaller hospitals (those diagnosing or treating fewer than 100 new primary cancer cases annually) are divided into four regions and assigned to one of four Regional Abstractors employed by KCR. The Regional Abstractors record and report information on all cases of cancer seen in these smaller institutions. The KCR Regional Coordinators and Regional Abstractors are required to be Certified Tumor Registrars (CTRs) or become CTRs within two years following their date of employment.

In 1994, the legislation requiring reporting of cancer cases was modified to include reporting from all health care facilities that either diagnose or treat cancer patients. These additional facilities include freestanding treatment centers, non-hospital (private) pathology laboratories, and physician offices (See [KRS 214.556](#)). In this same year, KCR received funding from the [Centers for Disease Control and Prevention \(CDC\)](#) through the National Program of Cancer Registries (NPCR). This additional funding allowed KCR to institute a formal quality assurance program, implement complete death clearance follow back, and hire staff to see that all cases of cancer were systematically reported by non-hospital facilities. All of these activities were initiated in 1994. Since 1995, KCR has collected uniform, high quality data on approximately 21,000 new primary cases of cancer occurring in Kentucky residents each year.

In 2000, KCR was selected as one of four expansion registries to become part of the National Cancer Institute's [Surveillance Epidemiology and End Results \(SEER\)](#) program. The SEER registries are considered to be among the most accurate and complete population-based cancer registries in the world. Funding from the SEER program has allowed KCR to further expand its quality control of activities and gather complete follow-up information.

Data from KCR have been submitted to the [North American Association of Central Cancer Registries \(NAACCR\)](#) for an objective evaluation of completeness, accuracy and timeliness each year since a formal certification program was established in 1997. In each year (1999 - 2001) KCR received the highest level of NAACCR certification available (Gold). KCR has also submitted its data for inclusion in the Cancer In North America (CINA) publication. A registry must have complete data for the most current five-year period before their data can be evaluated for inclusion in the CINA combined rates. KCR data have been included in the CINA combined rates each year since five years of KCR data have been available.

It is not enough to collect complete, accurate, and timely cancer data. These data are of limited value unless they are used to initiate cancer control programs, evaluate intervention activities, or conduct epidemiological research. KCR has worked very hard to ensure that the data collected are both useful and used.

KCR data have been used in preparing hundreds of research projects and proposals. Individual researchers interested in using data from KCR should consult the "Research" section of this web site (when it becomes available) or contact the KCR office.

It is important to note that KCR is part of an integrated cancer control effort of the [Markey Cancer Control Program](#). Data from KCR are presented each year to cancer councils in 15 Area Development Districts (groups of counties) covering the entire state. These District Cancer Councils use the data from KCR to identify specific types of cancer that occur in their area at substantially different rates compared to state and U.S. rates.

The data are presented as maps and focus on cancers for which there are scientifically proven cancer control interventions. This process has allowed sub-geographic areas of the state to identify cancer control issues that could not have been seen without a population-based cancer registry and to target their limited resources. The process has resulted in the implementation of many cancer control interventions intended to reduce identified cancer control problems and KCR data continue to be used to monitor the impact of these interventions.

**News:** Part 1 of the CSv2 Changes presentations is now available on the [Training](#) page.

## Navigation

- [About the Kentucky Cancer Registry](#)
- [Research](#)
- [cancer-rates.info](#)
  - [Cancer Incidence Rates](#)
  - [Cancer Mortality Rates](#)
- [Technical Resources](#)
  - [Software](#)
  - [In the Abstract](#)
  - [KCR Manuals Online](#)
  - [Technical Support/Software Updates](#)
  - [Training](#)
- [Annual Report](#)
- [Contact Us](#)

All underlined items are links to additional information available [www.kcr.uky.edu](http://www.kcr.uky.edu)

## Kentucky Cancer Consortium

### What is the Kentucky Cancer Consortium?

The Consortium is a statewide partnership of diverse organizations united to reduce the burden of cancer in Kentucky. Pooling information, ideas, skills and strategies, this partnership of organizations develops and implements cancer control initiatives that will decrease the suffering and deaths due to cancer for all Kentuckians.

See our [key messages](#) at [www.kycancerc.org](http://www.kycancerc.org)

### What does the Consortium do?

The Consortium provides a common forum for like-minded organizations to take collective action. Through group consensus at committee meetings and biannual statewide [KCC summits](#), the Consortium determines common priorities, prevents overlap, maximizes resources, and evaluates impact. Its priorities are guided by the state's [Cancer Action Plan](#), a comprehensive blueprint for reducing cancer in Kentucky.

### **What do Consortium members do?**

Members assess changing cancer control needs, set priorities, participate in meetings and conference calls, and share resources and knowledge with one another. Ultimately, Consortium members do more together than they ever could by working on their own.

### **How do individual members stay informed?**

The Consortium keeps the information flowing via face-to-face meetings, a newsletter, an electronic listserv, a Website, and other avenues, as outlines in the [KCC communication Plan](#).

### **How does the Consortium fit in with the national comprehensive cancer control program?**

The Centers for Disease Control and Prevention (CDC) funds and supports the Consortium as Kentucky's comprehensive cancer control coalition. We are one of the 64 state, tribal and territorial programs participating in the national CDC program.

### **How can I get involved?**

To inquire about membership or learn more about active committees and current Consortium priorities, contact [Jennifer Redmond](#), Program Director, Kentucky Cancer Consortium, at 859-219-0772 ext. 252.

## **Colon Cancer Prevention Project**

### **Our Mission**

The mission of the Colon Cancer Prevention Project is to eliminate preventable colon cancer death and suffering by increasing screening rates through education, advocacy and health systems improvement in Kentucky and surrounding communities.

### **Legislation**

Over the past year, the Project worked closely with Kentucky lawmakers to craft and pass two new state laws, KRS § 304.17A-247 ("Coverage under health benefit plan for colorectal cancer examinations and laboratory tests") and KRS §§ 214.540-544 ("Kentucky Colon Cancer Screening Program")

The first requires insurers to cover colorectal screening procedures for Kentuckians 50 and older and those considered at risk under the American Cancer Society guidelines. [Click here](#) or go to [www.c2p2.org](http://www.c2p2.org) to read this legislation.

The second law creates a program to screen the 15% of Kentuckians who are uninsured and an accompanying awareness campaign to educate all Kentuckians about colon cancer risk factors and prevention, though the state has yet to fund the program. The Project is working with the Kentucky Colon Cancer Screening Program Advisory

Committee and other statewide partners to secure funding for this vitally important program. [Click here](#) or go to [www.c2p2.org](http://www.c2p2.org) to read this legislation.

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#### **How did we get here?**

On Wednesday, April 2, 2008, the Colon Cancer Prevention Project came closer to achieving their mission when the Kentucky Senate passed the Kentucky Colon Cancer Screening Act (HB 415) with a 38 to 0 vote. The House, led by bill sponsor Chairman Tom Burch, passed the bill February 26, 2008 with a 94 to 0 vote. Governor Steve Beshear signed the Act into law on April 15, 2008 in the Rotunda of the Capitol in Frankfort.

The Act establishes a colon cancer screening program within the Kentucky Department of Public Health to provide screening services to uninsured individuals age 50 to 64 and others at high risk. The Kentucky Colon Cancer Screening Program will ensure that all Kentuckians will be educated as to the need for this cancer screening, and will assist and navigate the uninsured to seek the screening necessary to save lives.

Colon cancer is the third most commonly occurring cancer and the second leading cause of cancer deaths in Kentucky. Data from the Kentucky Cancer Registry show that there are an estimated 2,753 new colon cancer cases diagnosed and 930 deaths from colon cancer annually.

# Kentucky Cancer Program

Each year, about 20,820 Kentuckians are diagnosed with cancer, and 9,160 die from the disease. That's an average of 57 new cancer diagnoses and 25 cancer deaths in our state every day. The mission of the Kentucky Cancer Program (KCP) is to promote education, research and service programs to reduce this heavy cancer burden in our state. <http://www.kcp.uky.edu/AboutUs.html>

## **We are unique.**

The KCP is recognized nationally as a unique program that is state-funded, university-affiliated, and community-based. The KCP was created in 1982 and is jointly administered by the University of Kentucky [Lucille Parker Markey Cancer Center](#) and the University of Louisville [James Graham Brown Cancer Center](#). The partnership with Kentucky's two major academic institutions and cancer centers enables KCP activities to be based on science, driven by the latest and most accurate cancer data, and interwoven with research efforts.

## **We are community-based.**

The KCP operates through a network of 13 regional offices staffed by trained and experienced cancer control specialists who provide local leadership on cancer prevention and control initiatives for all of Kentucky's 120 counties. The KCP works closely with the [Kentucky Cancer Registry](#) and 15 District Cancer Councils across the state to identify and develop interventions/solutions to address cancer problems in their communities.

## **We are dedicated to education, research and service.**

The KCP provides a variety of cancer programs and services to health professionals, the public, patients and survivors. Collaboration is at the heart of all we do. The KCP establishes partnerships and works closely with state and local health departments, the Cooperative Extension Service, the Kentucky Cancer Registry, the American Cancer Society, the National Cancer Institute's Cancer Information Service, and other national, state and local organizations.

With our partners, the KCP has four major goals:

- Increase awareness of cancer prevention and risk factors.
- Increase cancer screenings and early prevention.
- Increase access to cancer treatment and care resources.
- Improve the quality of life for cancer survivors.

## **Pathfinder**

The KCP has developed a series of comprehensive guides to local cancer services and resources for each Area Development District. The guides, called Pathfinder, are updated annually. The guides are in PDF format. Download the guide for your area by clicking on your district at this link. <http://www.kcp.uky.edu/pathfinder.html>

# **SECTION V**

# Mass Media and Public Awareness

## Overview

The Kentucky Colon Cancer Screening Program carries out marketing and promotional efforts including general public awareness and education through the KY Educational Colon Tour and local patient outreach through partners.

General media and awareness resources, posters and brochures, are available for downloading at the following websites:

[http://chfs.ky.gov/dph/colon\\_cancer.htm](http://chfs.ky.gov/dph/colon_cancer.htm)

<http://www.coloncancerpreventionproject.org/ccppmedia/index.html>

<http://kycancerprogram.org/>

Links to resources that are available through other organizations are also available. Most materials are available in both English and Spanish.

Center for Disease Control and Prevention (PSA, Screen for Life)

<http://www.cdc.gov/cancer/colorectal/>

American Cancer Society (PSA, Brochures, Video Tapes) at

<http://www.cancer.org/docroot/home/index.asp>

National Cancer Institute (Brochures, Fact Sheets)

<http://www.cancer.gov/cancertopics/types/colon-and-rectal>

Other types of media will be developed and provided as funding permits. Marketing efforts will focus on the general public and the medically underserved population

Regional outreach and education on cancer awareness is coordinated through the Kentucky Cancer Program District Cancer Councils through state general funding from the University of Kentucky and the University of Louisville.

Information about the Kentucky Colon Cancer Screening Program can also be found through the following Cabinet for Family Services, Department for Public Health website, [http://chfs.ky.gov/dph/colon\\_cancer.htm](http://chfs.ky.gov/dph/colon_cancer.htm), and the Kentucky Cancer Consortium website, <http://www.kycancerc.org/>

## HONOR GOD'S TEMPLE.



Take care of your body.  
Get regular checks  
for colon cancer.



### DID YOU KNOW ...

- ✓ All Kentuckians age 50 and older should get regular colon cancer checks.
- ✓ Early colon cancer may have no symptoms.
- ✓ 9 out of 10 colon cancers may be prevented or cured with regular checks.

### NOW YOU KNOW

#### NOW YOU CAN



Talk to your doctor  
about getting checked  
for colon cancer

Kentucky Department for Public Health  
Colon Cancer Screening Program  
<http://chta.ky.gov/dph/ColonCancer.htm>

Bookmarks

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Regular  
colon cancer  
checks may  
**save**  
***your life!***

Kentucky Dept. for Public Health  
Colon Cancer Screening Program

[http://chfs.ky.gov/dph/  
ColonCancer.htm](http://chfs.ky.gov/dph/ColonCancer.htm)

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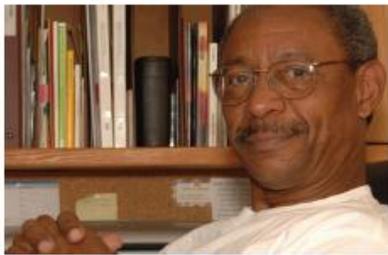
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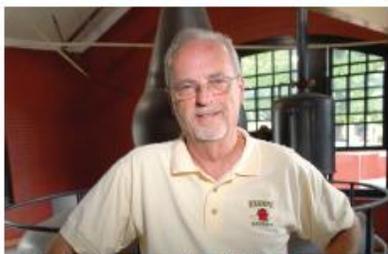
Curtis Hancock, farmer, Fulton



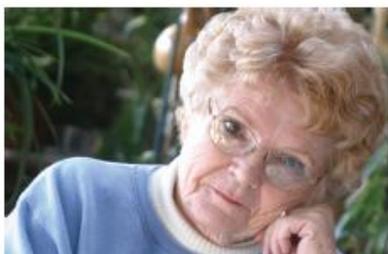
Jane Gentry Vance, poet, Lexington



John Huggins, retired educator, Louisville



Jim Rutlege, master distiller, Lebanon



Pat Brunner, homemaker, Berea

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## NOW YOU CAN

Talk to your doctor  
about getting checked  
for colon cancer



Kentucky Department for Public Health  
Colon Cancer Screening Program  
<http://chfs.ky.gov/dph/ColonCancer.htm>

*Photographs courtesy of Kentucky Monthly  
and photographers Steve Patton, Tim Webb,  
Warren Brunner, and Ann Stroth*

## The Kentucky Educational Colon



The KY Educational Colon Tour is a statewide colon cancer education and awareness program by the Kentucky Department for Public Health, the Louisville Metro Health Department and the Pike County Health Department. This is done in collaboration with health departments, Kentucky Cancer Program, the Colon Cancer Prevention Project and the Kentucky Cancer Consortium. For contact information to rent the KY Educational Colon, please contact Susan Reffett, RN, at 502-564-7996 x 3158 or at [Susan.Reffett@ky.gov](mailto:Susan.Reffett@ky.gov), The Pike County Health Department at 606-437-5500 or Suetta Clevinger at [Suetta.Clevinger@ky.gov](mailto:Suetta.Clevinger@ky.gov) and Linda Hall at [Linda.Hall@ky.gov](mailto:Linda.Hall@ky.gov). The Louisville Metro Health Department at 502-514-6530 or Leanne French at [Leanne.French@louisvilleky.gov](mailto:Leanne.French@louisvilleky.gov)

# Appendix

## SAMPLE COLONOSCPY PREP INSTRUCTIONS

### Bisacodyl and Haftlytely Prep

RULES MUST BE FOLLOWED OR RISK INACCURATE RESULTS!

- Rule # 1 Stop all Blood Thinner and Aspirin five to seven days prior to your colonoscopy and do not resume taking this medication until instructed to do so by your doctor.
- Rule # 2 Do not eat solid food or milk products beginning the day before your colonoscopy, until after the colonoscopy is done and your are given instructions.
- Rule # 3 You **MUST** drink at least 8 oz of liquids every hour all day, the day before your colonoscopy. This is the list of what you can have. If it is not on the list, you cannot have to eat or drink.
- Apple Juice, White Grape Juice, Lemonades, Water, Clear Chicken or Beef Broth or Bouillon, Ginger-Ale, Coffee or Tea (without milk or non dairy creamer). Gatorade, Crystal Lite, Plain Jello ( without fruit or toppings), Iced Popsicle, Kool-Aid and Fizzy or non Fizzy soft drinks such as Pepsi or Coke products.  
**Do not eat or drink anything that is RED or Purple. You must drink at least 64 oz of fluid before drinking the Haftlytely mixture at 6:00 pm.**
- Rule # 4 The morning before your colonoscopy take disposable container, add desired flavor pack and add room temperature water to the line and shake mixture well until the powder is dissolved and put the solution in the refrigerator until time to drink at 6:00 pm.
- Rule # 5 The day before your colonoscopy take two Bisacodyl Tablets at NOON. Drink a cup of broth, eat a cup of jello-o and drink eight oz of liquid from the list with the tablets.
- Rule # 6 The day before your colonoscopy at 6:00 pm, start drinking the Haftlytely Solution. Drink 8 oz every fifteen minutes until you complete the whole jug. Drink each glass quickly.
- Rule # 7 You must continue to drink from the list of Rule # 3 until the time of the colonoscopy. If your bowel movements are pale yellow and watery, you are **NOT** properly prepared for your colonoscopy.
- Rule # 8 You must have someone drive you home after your colonoscopy.

## Sample Colonoscopy Fact Sheet

Before this test, you will take a strong laxative to cleanse the colon. Colonoscopy is conducted in a doctor's office, clinic, or hospital. You are given a sedative to make you more comfortable, while the doctor uses a narrow, flexible, lighted tube to look inside the rectum and the entire colon. During the exam, the doctor may remove some polyps and collect samples of tissue or cells for more testing. For patients over 50, this test is recommended every 10 years.

Colonoscopy is the visual examination of the large intestine (colon) using a lighted, flexible fiberoptic or video endoscope. The colon begins in the right-lower abdomen and looks like a big question mark as it moves up and around the abdomen, ending in the rectum. It is 5 to 6 feet long. The colon has a number of functions including withdrawing water from the liquid stool that enters it so that a formed stool is produced.

### Why the test is performed?

There are many types of problems that can occur in the colon. The medical history, physical exam, laboratory tests and x-rays can provide information useful in making a diagnosis. Directly viewing the inside of the colon by colonoscopy is usually the best exam.

**Colonoscopy is used for:** ▪ Colon cancer -- a serious but highly curable malignancy ▪ Polyps -- fleshy tumors which usually are the forerunners of colon cancer ▪ Colitis (ulcerative or Crohn's) -- chronic, recurrent inflammation of the colon ▪ Diverticulosis and diverticulitis -- pockets along the intestinal wall that develop over time and can become infected ▪ Bleeding lesions -- bleeding may occur from different points in the colon ▪ Abdominal symptoms, such as pain or discomfort, particularly if associated with weight loss or anemia ▪ Abnormal barium x-ray exam ▪ Chronic diarrhea, constipation, or a change in bowel habits ▪ Anemia

### Preparation

To obtain the full benefits of the exam, the colon must be clean and free of stool. The patient receives instructions on how to do this. It involves drinking a solution which flushes the colon clean or taking laxatives and enemas. Usually the patient drinks only clear liquids and eats no food for the day before the exam. The physician advises the patient regarding the use of regular medications during that time.

The procedure takes 15 to 30 minutes and is seldom remembered by the sedated patient. A recovery area is available to monitor vital signs until the patient is fully awake. It is normal to experience mild cramping or abdominal pressure following the exam. This usually subsides in an hour or so.

### Results

After the exam, the physician explains the finding to the patient and the family. If the effects of the sedatives are prolonged, the physician may suggest an appointment at a later date. If a biopsy has been performed or a polyp removed, the results of these are not available for three to seven days.

## **Benefits**

A colonoscopy is performed to identify and/or correct a problem in the colon. The test enables a diagnosis to be made and specific treatment can be given. If a polyp is found during the exam, it can be removed at that time, eliminating the need for a major operation later. If a bleeding site is identified, treatment can be administered to stop the bleeding. Other treatments can be given through the endoscope when necessary.

## **Side Effects and Risks**

Bloating and distension typically occur for about an hour after the exam until the air is expelled. Serious risks with colonoscopy, however, are very uncommon. One such risk is excessive bleeding, especially with the removal of a large polyp. In rare instances, a tear in the lining of the colon can occur. These complications may require hospitalization and, rarely, surgery. Quite uncommonly a diagnostic error or oversight may occur.

Due to the mild sedation, the patient should not drive or operate machinery following the exam. For this reason, someone should be available to drive the patient home.

# COLORECTAL CANCER SCREENING PROGRAM GENTRACK DATA FORM

## 1. CLIENT AND RECORD IDENTIFICATION

First Name (Required)	Middle Name (Required)	Last Name (Required)	Social Security Number (Required) ____/____/_____
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## 2. DEMOGRAPHIC INFORMATION

<b>Date of Birth</b> __/__/____	<b>Gender</b> Circle One: Male Female	<b>Hispanic or Latino Origin? (Required)</b> Circle One: Yes No Unknown	<b>Race 1 (Required)</b> Circle One: White Black Asian Other Unknown
<b>Current Address Line 1</b>			
<b>Current Address Line 2</b>			
<b>Current City</b>		<b>Current State of Residence</b>	
<b>Current Zip Code</b>		<b>Current County of Residence</b>	
<b>Primary Phone</b>	<b>Secondary Phone</b>	<b>Email Address</b>	

## 3. SCREENING HISTORY

<b>3.1 Has client <span style="color: red;">ever</span> had a colorectal screening test?</b> A CRC screening test is limited to one of the following: Take-home FOBT; Take-home FIT; Sigmoidoscopy; Colonoscopy; DCBE; CTC; Stool DNA	<b>Circle One:</b> 1=Yes 2=No 3=Unknown
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## 4. ASSESSED RISK

4.1 Does the Client have a Personal history of CRC or precancerous polyps?	<b>Circle One:</b> 1=Yes 2=No 3=Unknown
4.2 Does the Client have a Biological Family history of CRC? (Do not include precancerous polyps)	<b>Circle One:</b> 1=Yes 2=No 3=Unknown
4.3 Is the Client currently experiencing CRC symptoms such as rectal bleeding, lower abdominal pain, bloody stools or marked change in bowel habits such as diarrhea or constipation, and significant unexplained weight loss?	<b>Circle One:</b> 1=Yes 2=No 3=Unknown

## 5. SCREENING SCHEDULE AND ADHERENCE

<b>5.1 Scheduled date</b> (appointment) for initial screening test OR date fecal kit was given to client.	____/____/____ DD/MM/YYYY
5.2 Screening adherence – Did the Client appear for their <b>appointment or return</b> the FOBT/FIT <b>test on schedule?</b> Refer to program guidelines as to when a fecal kit is deemed unreturned, or how much time can elapse before a client is considered an appointment no show.	Circle One: 1= Test Performed 2= Test Pending <i>[If #2 circled indicate dates of follow-up phone calls or letters in next section]</i> <b>3= No test performed, FOBT/FIT card not returned</b> <b>4=No test performed, appointment not kept</b> <b>[If # 3 or #4 is circled no further data is entered and the record is closed)</b>

<i>Follow-up Letter Sent Date</i>	<i>Follow-up Phone Call Date</i>
<i>Follow-up Comments</i>	

### 6.1 INFORMATION ABOUT THE SCREENING TEST PERFORMED

<b>6.0 What was the clinical reasoning for the type of screening test performed?</b> Circle One: 1=Screening 2= Surveillance 3= Diagnostic 9= Unknown		
<b>6.1.01 Which Test was performed?</b> Circle One: 1=Take Home FOBT 2=Take Home FIT 3=Sigmoidoscopy 4=Colonoscopy 5=DCBE 7=Other Specify Other Test _____		
<b>6.1.03 Date of Test 1</b> (Date) ____/____/____ MM DD YYYY		
<b>6.1.04 Provider Specialty for Test 1</b>		
If 6.1.04 = 3, 4, or 6, then complete the provider information		
1 = General practitioner 2 = Internist 3 = Family practitioner 4 = Gastroenterologist 5 = General surgeon 6 = Colorectal surgeon 7 = Licensed practical nurse 8 = Registered nurse 9 = Nurse practitioner 10 = Physician assistant 11 = Administrator, if FOBT/FIT mailed by non-clinician 12=Radiologist 13=Obstetrician/Gynecologist (OB/GYN) 99 = Unknown		
Provider First Name		Provider Last Name
Address Line 1		
Address Line 2		
City		State
Phone		Zip Code
Fax		E-Mail
<b>6.1.05 What were the test results?</b> 1 = Normal/Negative/Diverticulosis/hemorrhoids 2 = Other finding not suggestive of cancer or polyp(s) 3 = Polyp(s) or Lesion(s) suspicious for cancer 4 = Inadequate/Incomplete test with no findings 5 = FOBT/FIT/Other Test Performed Negative 6=FOBT/FIT/Other Test Performed Positive 7=Results are still pending 9 = Results are Unknown		
<b>6.1.06 Was a biopsy/polypectomy performed during the endoscopy?</b> Circle One 1 = Yes 2 = No 9 = Unknown	<b>6.1.07 Did the procedure report state that bowel prep was adequate?</b> (Leave blank if a FOBT or FIT test was used.) Circle One 1 = Yes 2 = No 9 = Unknown	<b>6.1.08 Was the cecum reached during the colonoscopy?</b> Circle One 1 = Yes 2 = No 9 = Unknown
<b>6.1.09 What was the outcome of the screening test? Test outcome</b> If 6.1.05 = 5 or 6, (FOBT or FIT) then 6.1.09 should = 1 (Complete). If 6.1.05 = 4 (test result inadequate or incomplete with no findings), then 6.1.09 should = 2 (Incomplete/Inadequate) If 6.1.07 = 2 (bowel prep not adequate), then 6.1.09 should = 2 (Incomplete/Inadequate) If 6.1.08 = 2 (cecum not reached), then 6.1.09 should = 2 (Incomplete/Inadequate) 1=Complete 2= Incomplete/Inadequate		
<b>6.1.10 If an additional follow up procedure was recommended – indicate which procedure or indicate NONE if no follow up needed at this time.</b> Circle One: 1 = Sigmoidoscopy 2 = Colonoscopy 3 = DCBE 4 = Surgery to complete diagnosis* (Section 8 below must be completed if this is circled) 7 = Other Test 6.1.11 _____ 8 = None (cycle is complete)		

### 7. PATHOLOGY FROM ALL ENDOSCOPY TESTS

Complete the pathology section if a biopsy or polypectomy was performed during any Test
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Pathologist First Name		Pathologist Last Name	
Pathology Report #	Pathology Report Date	Date Report Received at LHD	
Name of Pathology Lab		Path Lab Phone	
Path Lab Address 1			
Path Lab Address 2			
Pathology Lab City	Path Lab State	Path Lab Zip Code	
<b>7.1 Histology of most severe polyp/lesion</b> (as determined at time of initial procedure – do not change this item based on later procedures or surgeries)  If 7.1 = 4-11, then 7.2 and 7.3 below must be completed.		1 = Normal or other non-polyp histology 2 = Non-adenomatous polyp (inflammatory, hamartomatous, etc.) 3 = Hyperplastic polyp 4 = Adenoma, NOS (no high grade dysplasia noted) 5 = Adenoma, tubular (no high grade dysplasia noted) 6 = Adenoma, mixed tubular villous (no high grade dysplasia noted) 7 = Adenoma, villous (no high grade dysplasia noted) 8 = Adenoma, serrated (no high grade dysplasia noted) 9 = Adenoma with high grade dysplasia (includes in situ carcinoma) 10 = Adenocarcinoma, invasive 11 = Carcinoma, other 99 = Unknown/other lesions ablated, not retrieved or confirmed <i><b>Histologies for all polyps/lesions should be reviewed and a final diagnosis recorded in Item 9.2.</b></i>	
<b>7.2 Total number of adenomatous polyps/lesions</b> Do not include information from surgical resections in this section. Leave blank if no adenomatous lesions		Enter # 0 to 96 polyps/lesions _____ Enter 97 if 97 or more lesions _____ Enter 98 if there is at least one adenomatous lesion but unsure of exact number _____ Enter 99 if you do not know if there were ANY adenomatous lesions _____	
<b>7.3 Size of Largest Adeno Polyp</b>		1 = $\leq$ 1 cm 2 = $\geq$ 1 cm 9 = Unknown	

## 8. DIAGNOSIS INFORMATION FOR SURGERIES

<b>8.1 Histology from surgical resection</b> Use histology from surgical resection in conjunction with histology of the most severe polyp/lesion reported in item 7.1, to report the "Final diagnosis" (Item 9.2)  If no surgery was recommended (6.10 not = 4), then leave blank.  If surgery was recommended (6.10 = 4) but was not performed, then 8.1 should = 0 (Surgery recommended but not performed).	0 = Surgery recommended but not performed 1 = Normal or other non-polyp histology 2 = Non-adenomatous polyp (inflammatory, hamartomatous, etc.) 3 = Hyperplastic polyp 4 = Adenoma, NOS (no high grade dysplasia noted) 5 = Adenoma, tubular (no high grade dysplasia noted) 6 = Adenoma, mixed tubular villous (no high grade dysplasia noted) 7 = Adenoma, villous (no high grade dysplasia noted) 8 = Adenoma, serrated (no high grade dysplasia noted) 9 = Adenoma with high grade dysplasia (includes in situ carcinoma) 0 = Adenocarcinoma, invasive 11 = Cancer, other 99 = Unknown/other lesions ablated, not retrieved or confirmed <i>Use histology from surgical resection in conjunction with histology of the most severe polyp/lesion reported in item 7.1, to report the "Final diagnosis" (9.2).</i>
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<b>8.2 Date surgery performed</b> If 8.1 = 1-11, 99, then complete this field; otherwise, leave blank.	_____ / _____ / _____ MM                  DD                  YYYY
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## 9. FINAL DIAGNOSIS, COMPLICATIONS AND NEXT SCREENING RECOMMENDATION

Complete for all CCDE records with at least one test performed

<b>9.01 Status of final diagnosis</b>  Clients coded below as 3 (refused), 4 (lost) or 5 (irreconcilable) should have an administrative close-out date reported at the far right in section 9.3 "Date of diagnosis".  <b>Circle One:</b> 1 = Complete (final diagnosis made) 2 = Pending final diagnosis 3 = Client refused diagnostic follow-up. 4 = Client lost to follow-up before final diagnosis was made. 5 = Irreconcilable ( <i>not possible to translate clinical scenario with data collection definitions</i> )	<b>9.02 Final diagnosis</b> <i>If the status of the final diagnosis (9.01) is marked COMPLETE – then record the final diagnosis – otherwise leave blank.</i> If the only test performed in the cycle was either FOBT or FIT, then complete this field as 1 (Normal/Negative). If 9.02 = 4 or 5, then 11.1 (Registry linkage status) must be completed. <b>Circle One:</b> 1 = Normal/negative 2 = Hyperplastic polyps 3 = Adenomatous polyp, no high grade dysplasia 4 = Adenomatous polyp with high grade dysplasia 5 = Cancer	<b>9.03 Date of final diagnosis /Administrative Close out Date</b>  Leave blank if status of final diagnosis is "Pending" in section 9.01  _____ / _____ / _____ MM          DD          YYYY
<b>9.04 Recommended screening or surveillance test for next cycle</b> Leave blank if 9.01 above – Status of Diagnosis is not "1=Complete" <b>Circle One:</b> 1 = Take-home FOBT 2 = Take-home FIT 3 = Sigmoidoscopy 4 = Colonoscopy 5 = DCBE 8 = None (use if client is terminally ill or no further tests recommended for other reason) 9 = Unknown	<b>9.05 Indication for screening or surveillance test for next cycle</b> Leave blank if 9.01 does not = 1 Leave blank if 9.04 = 8, 9  <b>Circle One:</b> 1 = Screening 2 = Surveillance after a positive colonoscopy and/or surgery	<b>9.06 Number of months before screening or surveillance test for next cycle</b> Leave blank if 9.01 does not = 1 Leave blank if 9.04 = 8, 9  Enter # 12 – 180 MONTHS _____  Enter 99 IF UNKNOWN _____
<b>9.07 and 9.08 Complications (1) of endoscopy or DCBE requiring observation or treatment</b> Report the worst of up to 2 serious complications of CRC testing occurring within 30 days of the test date and resulting in an emergency room visit, hospitalization or death. Report only one complication in each of 9.07 and 9.08.	<b>Circle 1 or 2 below – do not circle more than 2</b> 0 = No complications reported 1 = Bleeding requiring transfusion 2 = Bleeding NOT requiring transfusion 3 = Cardiopulmonary events (hypotension, hypoxia, arrhythmia, etc) 4 = Complication related to anesthesia 5 = Bowel perforation 6 = Post-polypectomy syndrome/excessive abdominal pain 7 = Death 8 = Other 9 = Unknown	
<b>9.09 OTHER Complications of endoscopy or DCBE - other specify</b>	If Other complications (# 8) is selected above in 9.07 or 9.08, please write in that other complication.  _____	

9.10 Were CRCCP funds used for any of these colorectal screening/diagnostic tests?	1= Yes 2 = No 9 = Unknown
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## 10. TREATMENT INFORMATION

Complete this section when Final Diagnosis (9.02) = 5. This section may be completed when Final Diagnosis (9.02) = 4.	
<b>10.1 Recurrent cancers</b> <i>Is this cancer a new primary or a recurrent cancer?</i>	1 = New CRC primary 2 = Recurrent CRC 3 = Non-CRC primary (metastasis from another organ) 9 = Unknown
<b>10.2 Status of treatment</b> These items must have an administrative close-out date reported in 10.3 "Date of treatment". If 9.02 = 4, then 10.2 may be completed; however, 10.2 may not = 3, 4 or 9. If 9.02 = 5, then 10.2 must be completed. Leave blank if 9.02 = 1, 2 or 3.	1 = Treatment started and/or completed 2 = Treatment pending 3 = Treatment not indicated due to polypectomy 4 = Treatment not recommended 5 = Treatment Refused 6 = Lost to Follow-up 9 = Unknown
<b>10.3 Date of treatment</b> If 10.2 = 1, 3-6, then complete this field. If 10.2 = 3-6, then an administrative close-out date is required. Leave blank if 10.2 = 2 or 9.	<b>Date of treatment</b> <i>Can be the date treatment began, when the client refused, or was determined to be lost to follow-up. Date that treatment began <b>maybe</b> the date of one of the tests. For instance, if a polypectomy was done and cancer was found <b>and removed</b>, the date that the polyp(s) was removed would also be the date that treatment began.</i>  <div style="text-align: center;">           _____ / _____ / _____            MM      DD      YYYY         </div>

## 11. REGISTRY INFO. FOR CANCER/DYSPLASIA

<b>Complete this section when Final Diagnosis (9.02) = 4 or 5</b>	
<b>11.01 Registry linkage status</b> Has this record been linked to the state cancer registry?	1=Pending Linkage 2= Linked, matched 3=Linked, not matched
<b>11.02 Registry date of diagnosis</b> [NAACCR data item #390] If not blank, must be a valid date. Leave blank if 11.01 = 1, 3.	<div style="text-align: center;">           _____ / _____ / _____            MM      DD      YYYY         </div>
11.03 Registry histologic type [NAACCR data item #522] Leave blank if 11.01 = 1, 3.	Range: 8000-9989  _____ A complete list of valid values/labels will be provided for reference in Chapter 3 of the Data User's Manual.
<b>11.04 Registry behavior</b> [NAACCR data item #523] Leave blank if 11.01 = 1, 3. Registry Behavior Code	0=Benign 1=Uncertain or borderline malignancy 2=Carcinoma in Situ 3=Malignant

<p><b>11.05 Registry primary site</b>  [NAACCR data item #400]  See SEER Program Coding and Staging Manual (pg 69):  <a href="http://seer.cancer.gov/manuals/2007/SPCSM_2007_mai.doc.pdf">http://seer.cancer.gov/manuals/2007/SPCSM_2007_mai.doc.pdf</a>  Leave blank if 11.01 = 1, 3</p>	<p>Range: C000-C999</p> <p><u>C</u> _ _ _ _</p> <p>NOTE: The 'C' must be included as part of the variable response in the CCDE file. For example Cecum = C180. A complete list of valid values/labels will be provided for reference in the CCDE User's Manual.</p>
<p><b>11.06 Registry CS-derived SS2000</b>  [NAACCR data item #3020]  See CS Staging Manual (pg 67) &amp; SEER Summary Staging Manual:  <a href="http://www.cancerstaging.org/cstage/csmanualpart1.pdf">http://www.cancerstaging.org/cstage/csmanualpart1.pdf</a>  <a href="http://seer.cancer.gov/tools/ssm/">http://seer.cancer.gov/tools/ssm/</a>  Leave blank if 11.01 = 1, 3</p>	<p>0=In Situ  1=Localized  2=Regional, direct extension onlu  3=Regional, regional lymph nodes only  4=Regional, extension and nodes  5=Regional, NOS  7=Distant  8=Not applicable  9=Unknown/Unstaged</p>
<p><b>11.07 Registry CS-derived AJCC stage group</b>  [NAACCR data Item #3000]  See CS Staging Manual (pg 65):  <a href="http://www.cancerstaging.org/cstage/csmanualpart1.pdf">http://www.cancerstaging.org/cstage/csmanualpart1.pdf</a>  Leave blank if 11.01 = 1, 3</p>	<p>Range: 00-99</p> <p>Valid values for CS-derived AJCC stage include: 00-02, 10-24, 30-43, 50-63, 70-74, 88, 90, 99.</p> <p>A complete list of valid values/labels will be provided for reference in the CCDE User's Manual.</p>
<p><b>11.08 Registry CS extension</b>  [NAACCR data Item #2810]  See CS Staging Manual (pg 272):  <a href="http://www.cancerstaging.org/cstage/csmanualpart2.pdf">http://www.cancerstaging.org/cstage/csmanualpart2.pdf</a>  A complete list of valid values/labels will be provided for reference in the CCDE User's Manual.  Leave blank if 11.01 = 1, 3</p>	<p>Range: 00-99</p> <p>Valid values for CS extension include: 00, 05, 10-16, 20, 30, 40, 42, 45, 46, 50, 55, 57, 60, 65, 66, 70, 75, 80, 95, 99.</p>
<p><b>11.09 Registry CS lymph nodes</b>  [NAACCR data Item #2830]  See CS Staging Manual (pg 274):  <a href="http://www.cancerstaging.org/cstage/csmanualpart2.pdf">http://www.cancerstaging.org/cstage/csmanualpart2.pdf</a>  A complete list of valid values/labels will be provided for reference in the CCDE User's Manual.  Leave blank if 11.01 = 1, 3</p>	<p>Range: 00-99</p> <p>Valid values for CS lymph nodes include: 00, 10, 20, 30, 80, 99.</p>
<p><b>11.10 Registry CS mets at diagnosis</b>  [NAACCR data Item #2850]  See CS Staging Manual (pg 275):  <a href="http://www.cancerstaging.org/cstage/csmanualpart2.pdf">http://www.cancerstaging.org/cstage/csmanualpart2.pdf</a>  A complete list of valid values/labels will be provided for reference in the CCDE User's Manual.  Leave blank if 11.01 = 1, 3</p>	<p>Range: 00-99</p> <p>Valid values for CS mets at diagnosis include: 00, 08, 10, 40, 50, 99.</p>

**11.11 Registry CS tumor size**

[NAACCR data Item #2800]

See CS Staging Manual (pg 371):

<http://www.cancerstaging.org/cstage/csmanualpart2.pdf>

Leave blank if 11.01 = 1, 3

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001-988 = Exact size in millimeters

989 = is > or = 989 millimeters

990 = Microscopic focus or foci only; no size of focus is given

991 = Described as less than 1 cm

992 = Described as between 1cm and 2cm

993 = Described as between 2cm and 3cm

994 = Described as between 3cm and 4cm

995 = Described as between 4cm and 5cm

998 = Diffuse

999 = Unknown; size not stated





## Reference List

1. American Cancer Society. Cancer Facts and Figures 2010. Atlanta: American Cancer Society, 2010.
2. American Cancer Society, Colorectal Cancer Facts and Figures 2008-2010. Atlanta: American Cancer Society, 2008
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5. Levin B, Lieberman DA, McFarland, et al. Screening and Surveillance for the Early Detection of Colorectal Cancer and Adenomatous Polyps, 2008: A Joint Guideline from the American Cancer Society
6. Rex DK, Kahi CJ, Levin, B, et al. Guidelines for colonoscopy surveillance after colon cancer resection: a consensus update by the US Multi-Society Task Force on Colon cancer and the American Cancer Society. [CA Cancer J Clin 2006;56:160-167.](#)
7. Smith RA, Cokkinides V, Eyre HJ. American Cancer Society guidelines for the early detection of colon cancer, 2003, [CA Colon Cancer J Clin 2003 Jan Feb;53\(1\):27 43](#)
8. US Multi-Society Task Force on Colorectal Cancer, and the American College of Radiology. *CA Cancer J Clin.* 2008;58
9. U.S. Preventive Services Task Force at: <http://www.ahrq.gov/clinic/uspstf08/colocancer/colors.htm>